

Demographic and socio-economic influences on community-based care and caregivers of people with dementia in China

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Abstract

Background: Dementia is a major public health challenge and China has the largest population with dementia in the world. However, dementia care and caregivers for Chinese are less investigated.

Objectives and design: To evaluate demographic and socio-economic influences on dementia care, management patterns and caregiver burden in a household community-dwelling-based survey, using participants' care receipts and Zarit scale.

Setting and participants: Rural and urban communities across six provinces of China comprising 4837 residents aged ≥ 60 years, in whom 398 had dementia and 1312 non-dementia diseases.

Results: People with dementia were less likely to receive care if they were living in rural compared to urban areas (Odd ratio (OR) = 0.20; 95%CI: 0.10–0.41), having education level below compared to above secondary school (OR = 0.24; 95%CI: 0.08–0.70), manual labourer compared to non-manual workers (OR = 0.27; 95%CI: 0.13–0.55), having personal annual income below RMB 10,000 yuan (£1000) compared to above (OR = 0.37; 95%CI: 0.13–0.74) or having four or more than compared to less four children (OR = 0.52; 95%CI: 0.27–1.00). Caregivers for dementia compared with those for non-dementia diseases were younger and more likely to be patients' children or children in-law, had lower education and spent more caring time. Caregiver burden increased with low education, cutback on work and caring for patients who were younger or living in rural areas, and this caregiver burden was three-fold greater than that for non-dementia diseases.

Conclusions: There are a number of inequalities in dementia care and caregiver burden in China. Reducing the socio-economic gap and increasing education may improve community care for people with dementia and preserve caregivers' well-being.

Keywords

Care burden, epidemiology, socio-economic inequality

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Introduction

Dementia is a chronic and progressive syndrome that affects cognitive function, behaviour and ability to perform basic activities of daily living (ADL). Dementia has become one of the world's biggest health issues and a major public health challenge that is escalating as elderly population continues to grow.¹ Globally, there are 44 million people living with dementia, which is estimated to reach 75 million by 2030 and 135 million by 2050.²

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Studies have shown that more than three quarters of people with dementia receive care in the community, with the majority of caregivers being females.³ The cost of care is higher for dementia than other diseases.⁴ Compared to care for people with non-dementia diseases, care for those with dementia has been shown to require more time⁵ and to be associated with increased risk of ill health to the caregivers.^{6,7} However, few studies have examined the association of socio-economic status (SES) with care received by people with dementia living in the community, and there is a lack of data on the associations between burden of caregivers with other factors such as characteristics of the caregivers. Furthermore, current knowledge about dementia care and its management patterns and burden on caregivers are predominately derived from studies undertaken in Western countries; therefore, extrapolation of these findings may not be applicable to other countries, particularly those with high economic development and epidemiologic transitions such as China.

China has the largest population of people with dementia in the world. In 2001, there were five million Chinese living with dementia,⁸ and this figure has approximately doubled a decade later.⁹ By 2040, the numbers of people with dementia will be as many in China as those in the entire developed world.⁸ However, data on social care for Chinese individuals with dementia, and patterns of their care and caregiver burden in the community have not been well documented. The income gap between rich and poor in China over the past three decades has widened dramatically,¹⁰ which may have significant impact on the care received by people with dementia. The present study aimed to evaluate the influences of demographic and socio-economic factors on care and care management patterns for individuals with dementia and to assess the burden of care from a household community-dwelling population in China.

Methods

Data procurement

Data were gathered by teams of trained interviewers who had completed surveys of mental illness in older people.^{11,12} Participants were interviewed in their own home. Permission for interview and informed consent were obtained from each participant or, if that was not possible, from the closest responsible adult (in 5%). The main interview included a general health and risk factors record; the Geriatric Mental State (GMS) questionnaire¹³ and other components of the 10/66 algorithm dementia research package which included the Community Screening Instrument for Dementia (CSI-D) cognitive test score (COGSCORE), the CSI-D

informant interview (RELScore) and the modified Consortium to Establish a Registry for Alzheimer's Disease (CERAD) 10-word list learning task with delayed recall.¹⁴ In the general health and risk factors component, details relating to socio-demography, social networks and support, and cardiovascular and other risk factors were recorded.¹² Socio-economic data included rural/urban domicile area, educational level, occupational class and annual personal and family incomes. Medical history of other chronic diseases including heart disease, stroke, diabetes, chronic kidney disease, chronic bronchitis, cancer, Parkinson's disease or epilepsy was also recorded.

The participants' level of physical difficulty was assessed by ADL scale questionnaire. The ADL scale consists of 14 items: 'having a bath or all-over wash', 'washing hands and face', 'putting on shoes and stockings/socks', 'doing up buttons and zips', 'dressing yourself other than the above', 'getting to and using the water closet', 'getting in and out of bed', 'self-feeding', 'shaving (men) or doing hair (women)', 'cutting your own toenails', 'getting up and down steps', 'getting around the house', 'going out of doors alone' and 'taking medicine'. The valid responses to these items were 'No difficulty alone' (score 0), 'Managing alone with difficulty' (score 1) or 'Cannot do alone' (score 2).

Participants

The study population was derived from participants in our multi-province studies of dementia in China, which included Hubei province, the four-provinces study and Anhui province (Figure 1).¹⁵ Methods of these studies have been previously described in detail.¹⁵ Briefly, between 2010 and 2011 a household survey in

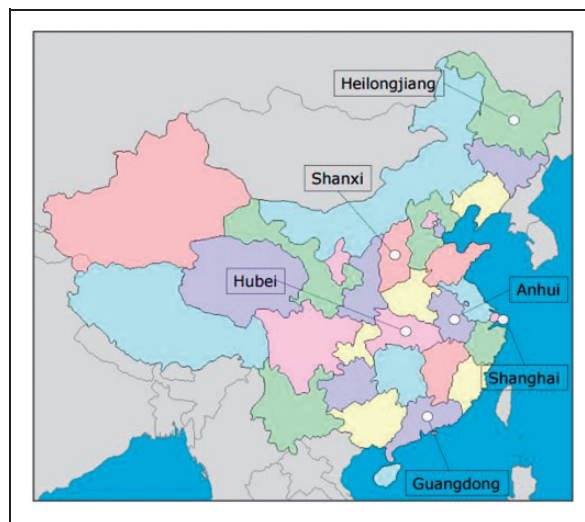


Figure 1. The six Chinese provinces in the present study.

Hubei province was conducted, employing a cluster randomised sampling method to choose residential communities. One rural community (Yanhe village in Wushan township of Wucheng county) and one urban community (Maojian sub-district in Shiyan city) were selected as the study fields. Based on the residential registration lists, we aimed to randomly recruit no fewer than 500 participants in each community. In total, 1001 participants aged ≥ 60 years were recruited, achieving a 91.8% response rate.

In the four-provinces study between 2008 and 2009, we selected one urban community and one rural community from each of four provinces (Guangdong, Heilongjiang, Shanghai and Shanxi) to recruit a random sample of 4314 participants aged ≥ 60 years for the survey of dementia in China (overall response rate 93.8%). Participants were interviewed using the general health and risk factors record, the GMS questionnaire and components of the 10/66 algorithm dementia research package in stage I. About 20% of participants were selected for stage II interview, which included the RELSCORE.¹⁵ Similarly, in 2007–2009 we completed the interview of 1757 older people aged ≥ 65 years, who were derived from the Anhui cohort study at third wave survey.¹⁵ Among these 6071 participants in the four-province and the Anhui surveys, we found that only 19.5% had data on care and caregivers, which were not used in the present study. Using the same protocol as that in the Hubei study, we re-interviewed the cohort members in 2010–2013. After excluding 329 deaths, we completed the interview for 3836 surviving cohort members.

Diagnosis of dementia

The GMS data were analysed by a computer program-assisted diagnosis, the Automated Geriatric Examination for Computer Assisted Taxonomy (AGECAT), to assess the principal mental disorders in the study participants.¹³ We used the 10/66 dementia algorithm to diagnose dementia, which has been widely used and validated in older adults with low educational levels in low- and middle-income countries including China.^{14,16} The 10/66 dementia diagnosis requires four inputs from the interview: the GMS-AGECAT diagnostic output, the COGSCORE, RELSCORE and CERAD 10-word list learning task with delayed recall.^{14,16} A cut-off point of probability (≥ 0.25) derived from the full 10/66 algorithm was used to diagnose dementia.

Informant data

In the informant questionnaire interview, we defined the informant to be the person who was best known to the

patient. They could be cohabitant of the participant, or non-cohabitant if they were better qualified to be the informant, a family member or a friend or neighbour if they were better qualified to be the informant. The amount of time spent with the patient was considered a criterion for choosing the most suitable informant if there were several co-resident family members. Characteristics of the informant, care arrangements for the patient, impact on the caregiver and clinical information about the older adult were documented. Whenever the patient received care and support, the main caregiver was selected as the informant for interview. The caregivers were asked about whether the patient received care a lot of time, occasionally or none at all.

Ethical approval was obtained from the Ethics Committee of School of Health and Wellbeing, University of Wolverhampton, UK, and from the Research Ethics Committee of Anhui Medical University and the local governments in China.

Statistical analysis

Differences in the proportions of care received by patients and in characteristics of their caregivers between people with dementia and people with non-dementia diseases were examined. Multivariate logistic regression models, with adjustments for confounding factors where necessary, were conducted to investigate the care received in relation to patients' SES and social network, and to assess the associations of caregivers' and patients' characteristics with burden of care. Determinants of caregiver burden were assessed by summing up 22 indicators of the Zarit scale for a total score of 22, and a score above the midpoint (>11) was considered as high burden of care for analysis. Analyses were performed using SPSS version 21.0 (SPSS Inc., Chicago, IL). Significance was accepted when $P < 0.05$.

Results

Of 4837 participants, there were 1710 patients with chronic diseases (398 patients with dementia and 1312 with non-dementia diseases) in whom 212 (12.4%) received care at home ranging from occasionally to a lot of time. Figure 2 shows that there were 33% of patients with dementia, 21% of patients with stroke, 3% of patients with heart disease and 3% patients with other diseases received care. After adjustments for age, sex, geographic provinces and ADL, people with dementia were 4.17-fold (95% confidence interval: 2.79–6.27) more likely to receive care compared to all patients with other diseases. Among people with dementia, we found that these living in rural areas, having lower levels of education, occupation and personal

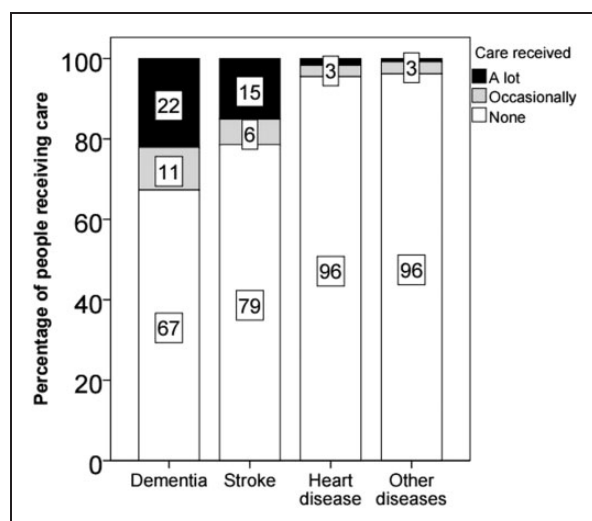


Figure 2. Percentage of people with dementia and other chronic diseases receiving care in China.

income, and having four or more children were less likely to receive care (Table 1), regardless of the severity of dementia and level of ADL.

Table 2 shows characteristics of caregivers for people with dementia and those with non-dementia diseases and patterns of care management. Compared to caregivers for people with non-dementia diseases, caregivers for people with dementia were more likely to be younger, have no school education, spend more time providing care and regularly involve a relative/friend for help. These caregivers were also more likely to be the patient's children or children-in-law. There were no significant differences with regard to sex, marital status, employment status, living with patients, cutback on work due to care or requesting financial assistance for care between caregivers of people with dementia and people with other diseases.

Caregivers for people with dementia had higher burden of care than caregivers for people with diseases other than dementia. Table 3 shows that 20 of the 22

Table 1. Proportions and odds ratios of the care received by people with dementia according to their demographic and socio-economic characteristics.

	Care received					Multivariate logistic analysis ^a		
	No (n = 268)		Yes (n = 130)		<i>P</i> ^b			
	n	(%)	n	(%)		OR	95%CI	<i>P</i>
Age (years)								
60–74	89	(33.2)	28	(21.5)	0.003	Referent		0.144
75–84	127	(47.4)	58	(44.6)		1.25	0.61–2.57	
≥85	52	(19.4)	44	(33.8)		2.18	0.96–4.91	
Sex								
Women	199	(74.3)	83	(63.8)	0.032	Referent		0.280
Men	69	(25.7)	47	(36.2)		1.40	0.76–2.57	
District								
Urban	52	(19.4)	52	(40.0)	< 0.001	Referent		< 0.001
Rural	216	(80.6)	78	(60.0)		0.20	0.10–0.41	
Educational level								
Secondary school or above	11	(4.1)	17	(13.1)	0.001	Referent		0.009
Primary school or below	257	(95.9)	113	(86.9)		0.24	0.08–0.70	
Occupational class								
Non-manual worker	51	(19)	39	(30.0)	0.014	Referent		< 0.001
Manual labourer	217	(81)	91	(70.0)		0.27	0.13–0.55	
Annual income (RMB Yuan)								
≥10,000	64	(23.9)	52	(40.0)	0.001	Referent		0.005
<10,000	204	(76.1)	78	(60.0)		0.37	0.19–0.74	
Annual family income per person (RMB Yuan)								
≥10,000	144	(53.7)	62	(47.7)	0.258	Referent		0.109
<10,000	124	(46.3)	68	(52.3)		0.59	0.31–1.13	

(continued)

Table 1. Continued

	Care received				<i>P</i> ^b	Multivariate logistic analysis ^a		
	No (n = 268)		Yes (n = 130)			OR	95%CI	<i>P</i>
	n	(%)	n	(%)				
Activity of daily living (score)								
0	223	(83.2)	32	(24.6)	< 0.001	Referent		< 0.001
1–4	25	(9.3)	20	(15.4)		2.79	1.27–6.10	
5–28	20	(7.5)	78	(60.0)		18.03	9.20–35.33	
Probability dementia diagnosed by 10/66 algorithm								
≥0.29–0.4	151	(56.3)	28	(21.5)	< 0.001	Referent		< 0.001
>0.4–0.6	42	(15.7)	21	(16.2)		2.03	0.87–4.73	
>0.6–1.0	75	(28)	81	(62.3)		4.15	2.15–8.00	
Social network and support								
Number of children								
0–3	94	(35.1)	42	(32.3)	0.585	Referent		0.049
≥4	174	(64.9)	88	(67.7)		0.52	0.27–1.00	
How far to your most closed relatives								
Outside county/city or no relatives	11	(4.1)	2	(1.5)	0.236	Referent		0.490
Within same town or district	257	(95.9)	128	(98.5)		1.94	0.30–12.80	
Frequency of visiting children/relatives								
Daily	86	(32.1)	34	(26.2)	0.341	Referent		0.170
<Daily and ≥Monthly 1	93	(34.7)	54	(41.5)		2.08	0.97–4.47	
<Monthly 0	89	(33.2)	42	(32.3)		1.63	0.73–3.64	
Frequency of contacting and speaking to friends in village/community								
Daily	82	(30.6)	30	(23.1)	0.246	Referent		0.353
<Daily and ≥Monthly	120	(44.8)	61	(46.9)		1.70	0.81–3.59	
<Monthly	66	(24.6)	39	(30.0)		1.24	0.53–2.94	
Help available when needed								
No	8	(3.0)	7	(5.4)	0.238	1.81	0.42–7.73	0.423
Yes	260	(97)	123	(94.6)				

^aAdjusted for age, sex, province, ADL and probability of dementia.^bChi-square test.

indicators measured by the Zarit scale were significantly worse (higher scores) for caregivers of people with dementia, and they remained significantly higher for 11 indicators after adjustments for age, sex and province. The high caregiver burden was three-fold greater ($P=0.002$) in caring for people with dementia than for people with non-dementia diseases.

Table 4 shows the risk for having high caregiver burden in relation to caregiver's characteristics and different factors of dementia patients. Apart from caring for people with dementia, high caregiver burden was significantly associated with caregivers' low education and cutback on their work due to care commitments, and also with care for younger patients and for those residing in rural areas. Other factors from patients did not relate to high caregiver burden. Data restricted to care for dementia (Table 5) showed similar patterns of results on caregiver burden for all conditions

but was less statistically significant. There were no associations between SES and care received by people with non-dementia diseases in the present study (Table 6).

Discussion

In this large-scale population-based study of Chinese individuals, we have identified significant inequalities in care of people with dementia in the community. Those with low SES were disproportionately less likely to receive care, regardless of mental and physical status. Dementia care in China imposed considerable burdens on caregivers, many of whom were patients' children or children in-law, young and had their education compromised. Burden of care significantly increased in caregivers for people with dementia who spent more time on care, had low education and

Table 2. Characteristics of caregivers for people with dementia and for those with non-dementia diseases.

	Caregivers for				<i>P</i> ^a	Multivariate logistic analysis		
	dementia (n = 130)		other disease (n = 82)			OR ^b	95%CI	<i>P</i>
	n	%	n	%				
Demographic characteristics								
Age (years)								
7–39	20	(15.4)	6	(7.3)	0.004	3.78	1.28–11.16	0.015
40–59	62	(47.7)	27	(32.9)		2.16	1.11–4.21	
60–95	48	(36.9)	49	(59.8)		Referent		
Sex								
Women	64	(49.2)	49	(59.8)	0.135	Referent		0.170
Men	66	(50.8)	33	(40.2)		1.57	0.83–2.97	
Marital status								
Married/cohabitated	120	(92.3)	72	(87.8)	0.490	Referent		0.486
Never married	6	(4.6)	7	(8.5)		0.47	0.13–1.69	
Separated/divorced	4	(3.1)	3	(3.7)		1.32	0.21–8.47	
Educational level								
≥Secondary school	41	(31.5)	34	(41.5)	0.145	Referent		0.031
Primary school	47	(36.2)	31	(37.8)		1.17	0.53–2.56	
No school	42	(32.3)	17	(20.7)		3.23	1.28–8.17	
Current employment status								
Retired	32	(24.6)	33	(40.2)	0.035	Referent		0.733
Unemployed (look for job)	64	(49.2)	36	(43.9)		1.37	0.63–2.96	
Employed	34	(26.2)	13	(15.9)		1.21	0.42–3.47	
Relationships with patient								
Relationship with patient ^c								
Spouse	31	(23.8)	39	(47.6)	0.004	Referent		0.008
Daughter/son	42	(32.3)	17	(20.7)		2.47	1.08–5.68	
Daughter/son-in-law	20	(15.4)	5	(6.1)		8.34	2.36–29.51	
Other relative	6	(4.6)	5	(6.1)		1.46	0.36–5.90	
Friend/ neighbour	11	(8.5)	9	(11.0)		1.69	0.53–5.42	
Other	20	(15.4)	7	(8.5)		4.23	1.43–12.50	
Normally living with older person								
No	27	(20.8)	11	(13.4)	0.174	Referent		0.229
Yes	103	(79.2)	71	(86.6)		0.59	0.24–1.40	
Methods of caring for patient								
Care time								
A little	42	(32.3)	43	(52.4)	0.004	Referent		0.027
A lot	88	(67.7)	39	(47.6)		2.09	1.09–4.04	
Have any other relatives or friends regularly help to care for older person								
No	86	(66.2)	67	(81.7)	0.014	Referent		0.008
Yes	44	(33.8)	15	(18.3)		2.86	1.31–6.22	
‘Shift’ care component								
One or more family members	103	(79.2)	64	(78.0)	0.838	Referent		0.406
One or more friends/neighbours	27	(20.8)	18	(22.0)		0.72	0.34–1.56	
Given up or cut down on work to care for older person								
No	94	(72.3)	66	(80.5)	0.178	Referent		0.171
Yes	36	(27.7)	16	(19.5)		1.72	0.79–3.74	

(continued)

Table 2. Continued

	Caregivers for				<i>P</i> ^a	Multivariate logistic analysis		
	dementia (n = 130)		other disease (n = 82)			OR ^b	95%CI	<i>P</i>
	n	%	n	%				
Anyone paid to help older person during the day								
No	102	(78.5)	67	(81.7)	0.567	Referent		0.789
Yes	28	(21.5)	15	(18.3)		0.90	0.40–2.02	
Anyone paid to help older person during the night								
No	108	(83.1)	74	(90.2)	0.145	Referent		0.252
Yes	22	(16.9)	8	(9.8)		1.78	0.66–4.79	

^aChi-square test.^bAdjusted for caregiver's age, sex and province location.^cSince this variable is highly related to caregiver's age, we adjusted for caregivers' sex and province location to avoid multicollinearity.**Table 3.** Zarit caregiver burden in caring for people with dementia and those with non-dementia chronic diseases.

	Caregivers for				<i>P</i> ^b	Multivariate logistic analysis ^a		
	dementia (n = 130)		other disease (n = 82)			OR	95%CI	<i>P</i>
	n	%	n	%				
ZB1: Do you feel that your relative asks for more help than he/she needs?								
No	48	(36.9)	44	(53.7)	0.017	Referent		0.028
Yes	82	(63.1)	38	(46.3)		2.13	1.08–4.17	
ZB2: Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?								
No	52	(40.0)	45	(54.9)	0.034	Referent		0.163
Yes	78	(60.0)	37	(45.1)		1.59	0.83–3.04	
ZB3: Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?								
No	58	(44.6)	47	(57.3)	0.072	Referent		0.236
Yes	72	(55.4)	35	(42.7)		1.48	0.77–2.82	
ZB4: Do you feel embarrassed over your relative's behaviour?								
No	75	(57.7)	60	(73.2)	0.022			0.391
Yes	55	(42.3)	22	(26.8)		1.36	0.67–2.77	
ZB5: Do you feel angry when you are around your relative?								
No	69	(53.1)	58	(70.7)	0.011	Referent		0.177
Yes	61	(46.9)	24	(29.3)		1.60	0.81–3.16	
ZB6: Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?								
No	75	(57.7)	55	(67.1)	0.172	Referent		0.823
Yes	55	(42.3)	27	(32.9)		1.08	0.55–2.10	
ZB7: Are you afraid what the future holds for your relative?								
No	53	(40.8)	46	(56.1)	0.029	Referent		0.188
Yes	77	(59.2)	36	(43.9)		1.58	0.80–3.10	
ZB8: Do you feel your relative is dependent upon you?								
No	37	(28.5)	39	(47.6)	0.005	Referent		0.102
Yes	93	(71.5)	43	(52.4)		1.81	0.89–3.68	
ZB9: Do you feel strained when you are around your relative?								
No	71	(54.6)	66	(80.5)	<0.001	Referent		0.007
Yes	59	(45.4)	16	(19.5)		2.73	1.32–5.63	

(continued)

Table 3. Continued

	Caregivers for				<i>p</i> ^b	Multivariate logistic analysis ^a		
	dementia (n = 130)		other disease (n = 82)			OR	95%CI	<i>P</i>
	n	%	n	%				
ZB10: Do you feel your health has suffered because of your involvement with your relative?								
No	73	(56.2)	60	(73.2)	0.013	Referent		0.013
Yes	57	(43.8)	22	(26.8)		2.39	1.20–4.76	
ZB11: Do you feel that you do not have as much privacy as you would like, because of your relative?								
No	61	(46.9)	59	(72.0)	<0.001	Referent		4.967
Yes	69	(53.1)	23	(28.0)		0.007	2.52–1.28	
ZB12: Do you feel that your social life has suffered because you are caring for your relative?								
No	63	(48.5)	56	(68.3)	0.005	Referent		0.040
Yes	67	(51.5)	26	(31.7)		2.02	1.03–3.97	
ZB13: Do you feel uncomfortable about having friends over, because of your relative?								
No	79	(60.8)	63	(76.8)	0.015	Referent		0.094
Yes	51	(39.2)	19	(23.2)		1.83	0.90–3.72	
ZB14: Do you feel that your relative seems to expect you to take care of her/him, as if you were the only one she/he could depend on?								
No	60	(46.2)	53	(64.6)	0.009	Referent		0.059
Yes	70	(53.8)	29	(35.4)		1.91	0.98–3.75	
ZB15: Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?								
No	67	(51.5)	59	(72.0)	0.003	Referent		0.004
Yes	63	(48.5)	23	(28.0)		2.71	1.37–5.36	
ZB16: Do you feel that you will be unable to take care of your relative much longer?								
No	66	(50.8)	59	(72.0)	0.002	Referent		0.049
Yes	64	(49.2)	23	(28.0)		2.00	1.00–4.01	
ZB17: Do you feel you have lost control of your life since your relative's illness?								
No	75	(57.7)	63	(76.8)	0.004	Referent		0.065
Yes	55	(42.3)	19	(23.2)		1.94	0.96–3.92	
ZB18: Do you wish you could just leave the care of your relative to someone else?								
No	67	(51.5)	60	(73.2)	0.002	Referent		0.027
Yes	63	(48.5)	22	(26.8)		2.16	1.09–4.28	
ZB19: Do you feel uncertain about what to do about your relative?								
No	55	(42.3)	60	(73.2)	<0.001	Referent		0.002
Yes	75	(57.7)	22	(26.8)		3.00	1.50–5.97	
ZB20: Do you feel you should be doing more for your relative?								
No	46	(35.4)	51	(62.2)	<0.001	Referent		0.003
Yes	84	(64.6)	31	(37.8)		2.78	1.42–5.46	
ZB21: Do you feel you could do a better job in caring for your relative?								
No	44	(33.8)	49	(59.8)	<0.001	Referent		0.010
Yes	86	(66.2)	33	(40.2)		2.45	1.24–4.86	
ZB22: Overall, how burdened do you feel in caring for your relative?								
No	48	(36.9)	52	(63.4)	<0.001	Referent		0.007
Yes	82	(63.1)	30	(36.6)		2.47	1.27–4.77	
ZB: Total score								
0–11	59	(45.4)	62	(75.6)	<0.001	Referent		0.002
12–22	71	(54.6)	20	(24.4)		3.01	1.49–6.05	

^aAdjusted for caregiver's age, sex and province location.^bChi-square test.

Table 4. Risk factors for high caregiver burden in caring for people with dementia and other non-dementia diseases.

	High caregiver burden ^a					Multivariate logistic analysis ^b		
	No (n = 121)		Yes (n = 91)		P ^c			
	n	%	n	%		OR	95%CI	P
Caregiver demographic characteristics								
Age (years)								
≤40	16	(13.2)	10	(11.0)	0.160	Referent		0.520
>40–59	44	(36.4)	45	(49.5)		1.77	0.64–4.85	
≥60	61	(50.4)	36	(39.6)		1.44	0.51–4.01	
Sex								
Women	65	(53.7)	48	(52.7)	0.888	Referent		
Men	56	(46.3)	43	(47.3)		0.85	0.45–1.61	0.625
Educational level								
Secondary school or above	52	(43.0)	23	(25.3)	0.008	Referent		
Primary school or below	69	(57.0)	68	(74.7)		2.55	1.23–5.29	0.012
Caregiver's relationships with patient								
Relationship with patient								
Spouse	39	(32.2)	31	(34.1)	0.356	Referent		0.181
Daughter/son	34	(28.1)	25	(27.5)		0.27	0.08–0.86	
Daughter/son-in-law	12	(9.9)	13	(14.3)		0.40	0.09–1.72	
Other relative	6	(5.0)	5	(5.5)		0.41	0.07–2.50	
Friend/neighbour	16	(13.2)	4	(4.4)		0.16	0.04–0.69*	
Other	14	(11.6)	13	(14.3)		0.38	0.09–1.64	
Living with patient								
No	24	(19.8)	14	(15.4)	0.403	Referent		
Yes	97	(80.2)	77	(84.6)		2.05	0.88–4.79	0.520
Methods of care for patient								
Stopped or reduced employment due to care								
No	102	(84.3)	58	(63.7)	0.001	Referent		
Yes	19	(15.7)	33	(36.3)		2.90	1.30–6.48	0.01
Relatives or friends help for care								
No	95	(78.5)	58	(63.7)	0.017	Referent		
Yes	26	(21.5)	33	(36.3)		1.84	0.89–3.79	0.098
Pay people for care at day								
No	101	(83.5)	68	(74.7)	0.117	Referent		
Yes	20	(16.5)	23	(25.3)		1.29	0.57–2.92	0.55
Pay people for care at night								
No	108	(89.3)	74	(81.3)	0.101	Referent		
Yes	13	(10.7)	17	(18.7)		1.16	0.45–2.95	0.764
Care time								
A little	59	(48.8)	26	(28.6)	0.003	Referent		
A lot	62	(51.2)	65	(71.4)		1.62	0.81–3.24	0.17
Characteristics of patients								
Age (years)								
60–74	30	(24.8)	24	(26.4)	0.185	3.66	1.41–9.50	
75–84	48	(39.7)	45	(49.5)		3.33	1.51–7.33	
≥85	43	(35.5)	22	(24.2)		Referent		0.006

(continued)

Table 4. Continued

	High caregiver burden ^a					P ^c	Multivariate logistic analysis ^b		
	No (n = 121)		Yes (n = 91)		OR		95%CI	P	
	n	%	n	%					
Sex									
Women	70	(57.9)	58	(63.7)		Referent		0.558	
Men	51	(42.1)	33	(36.3)		0.82	0.43–1.58		
District									
Urban	68	(56.2)	30	(33.0)		Referent		0.003	
Rural	53	(43.8)	61	(67.0)		2.99	1.47–6.08		
Educational level									
Secondary school or above	33	(27.3)	12	(13.2)				0.291	
Primary school or below	88	(72.7)	79	(86.8)		1.62	0.66–3.95		
Occupational class									
Non-manual worker	49	(40.5)	23	(25.3)		Referent		0.099	
Manual labourer	72	(59.5)	68	(74.7)		1.84	0.89–3.80		
Annual income (RMB yuan)									
≥10,000	60	(49.6)	34	(37.4)		Referent		0.170	
<10,000	61	(50.4)	57	(62.6)		1.58	0.82–3.01		
Annual family income per person (RMB yuan)									
≥10,000	68	(56.2)	45	(49.5)		Referent		0.545	
<10,000	53	(43.8)	46	(50.5)		1.23	0.62–2.44		
Activity of daily living (score)									
0–4	64	(52.9)	33	(36.3)		Referent		0.202	
5–28	57	(47.1)	58	(63.7)		1.57	0.79–3.12		
Patients' social network and support									
Number of children									
0–3	46	(38.0)	32	(35.2)		Referent		0.868	
≥4	75	(62.0)	59	(64.8)		0.95	0.49–1.82		
Frequency of visiting children/relatives									
Daily	30	(24.8)	22	(24.2)		Referent		0.258	
<Daily and ≥Monthly1	54	(44.6)	37	(40.7)		1.51	0.65–3.46		
<Monthly 0	37	(30.6)	32	(35.2)		2.10	0.87–5.09		
Help available when needed									
Yes	116	(95.9)	85	(93.4)		Referent		0.293	
No	5	(4.1)	6	(6.6)		2.06	0.54–7.92		

^aDefined as those having a score > 11 on Zarit Scale.^bChi-square test.^cAdjusted for age, sex, centre and care time of caregiver and severity of dementia and ADL level of the patients.

*P = 0.015

cutback on their work due to care commitments, and it was also associated with younger patients with dementia and those who lived in rural areas.

Comparison of care for patients with dementia and non-dementia diseases

Our findings of greater care received by patients with dementia than by those with non-dementia diseases,

who also required more time on care, are consistent with previous studies.^{1,15,17} People with dementia often require assistance with daily tasks, but as the condition deteriorates, one-to-one care is necessary to ensure safety due to the patients' behavioural change and help with their reduced mobility and ability to perform basic ADL. This increasing burden of care is accompanied by worsening levels of cognitive impairment. A study by Langa et al.¹⁷ has revealed that

Table 5. Risk factors for high caregiver burden in caring for people with dementia.

	High caregiver burden ^a					Multivariate logistic analysis ^b		
	No (n=59)		Yes (n=71)		P ^c			
	n	%	n	%		OR	95%CI	P
Caregivers' characteristics								
Age (years)								
≤40	11	(18.6)	9	(12.7)	0.470	Referent		0.596
>40–59	25	(42.4)	37	(52.1)		1.82	0.57–5.79	
≥60	23	(39.0)	25	(35.2)		1.57	0.48–5.11	
Sex								
Women	27	(45.8)	37	(52.1)	0.471	Referent		0.283
Men	32	(54.2)	34	(47.9)		0.64	0.29–1.44	
Educational level								
Secondary school or above	24	(40.7)	17	(23.9)	0.041	Referent		0.038
Primary school or below	35	(59.3)	54	(76.1)		2.69	1.06–6.84	
Caregiver's relationships with patient								
Relationship with patient								
Spouse	11	(18.6)	20	(28.2)	0.527	Referent		0.345
Daughter/son	21	(35.6)	21	(29.6)		0.21	0.04–1.04	
Daughter/son-in-law	7	(11.9)	13	(18.3)		0.52	0.08–3.49	
Other relative	3	(5.1)	3	(4.2)		0.16	0.02–1.71	
Friend/neighbour	7	(11.9)	4	(5.6)		0.17	0.03–1.04	
Other	10	(16.9)	10	(14.1)		0.25	0.04–1.72	
Living with patient								
No	14	(23.7)	13	(18.3)	0.448	Referent		0.478
Yes	45	(76.3)	58	(81.7)		1.46	0.51–4.17	
Methods of care for patient								
Stopped or reduced employment due to care								
No	49	(83.1)	45	(63.4)	0.013	Referent		0.061
Yes	10	(16.9)	26	(36.6)		2.72	0.96–7.74	
Relatives or friends help for care								
No	43	(72.9)	43	(60.6)	0.139	Referent		0.139
Yes	16	(27.1)	28	(39.4)		1.96	0.80–4.78	
Pay people for care at day								
No	48	(81.4)	54	(76.1)	0.464	Referent		0.855
Yes	11	(18.6)	17	(23.9)		0.91	0.33–2.51	
Pay people for care at night								
No	50	(84.7)	58	(81.7)	0.644	Referent		0.818
Yes	9	(15.3)	13	(18.3)		0.88	0.28–2.71	
Care time								
A little	22	(37.3)	20	(28.2)	0.268	Referent		0.243
A lot	37	(62.7)	51	(71.8)		1.66	0.71–3.87	
Patients' characteristics								
Age (years)								
60–74	12	(20.3)	16	(22.5)	0.025	2.62	0.82–8.32	
75–84	20	(33.9)	38	(53.5)		4.71	1.74–12.76	
≥85	27	(45.8)	17	(23.9)		Referent		0.010

(continued)

Table 5. Continued

	High caregiver burden ^a					Multivariate logistic analysis ^b		
	No (n=59)		Yes (n=71)		P ^c	OR	95%CI	P
	n	%	n	%				
Sex								
Women	38	(64.4)	45	(63.4)	0.903	Referent		0.865
Men	21	(35.6)	26	(36.6)		0.93	0.42–2.09	
District								
Urban	29	(49.2)	23	(32.4)	0.052	Referent		0.008
Rural	30	(50.8)	48	(67.6)		3.80	1.42–10.18	
Educational level								
Secondary school or above	9	(15.3)	8	(11.3)	0.502			0.361
Primary school or below	50	(84.7)	63	(88.7)		1.82	0.51–6.53	
Occupational class								
Non-manual worker	22	(37.3)	17	(23.9)	0.908	Referent		0.104
Manual labourer	37	(62.7)	54	(76.1)		2.26	0.85–6.02	
Annual income (RMB Yuan)								
≥10,000	24	(40.7)	28	(39.4)	0.886	Referent		0.591
<10,000	35	(59.3)	43	(60.6)		1.26	0.54–2.91	
Annual family income per person (RMB Yuan)								
≥10,000	29	(49.2)	33	(46.5)	0.761	Referent		0.76
<10,000	30	(50.8)	38	(53.5)		1.14	0.49–2.69	
Activity of daily living (score)								
0–4	25	(42.4)	27	(38.0)	0.615	Referent		0.540
5–28	34	(57.6)	44	(62.0)		1.30	0.56–3.02	
Probability dementia diagnosed by 10/66 algorithm								
≥0.29–0.4	17	(28.8)	11	(15.5)	0.175	Referent		0.330
>0.4–0.6	8	(13.6)	13	(18.3)		2.29	0.63–8.29	
>0.6–1.0	34	(57.6)	47	(66.2)		1.96	0.74–5.17	
Social network and support								
Number of children								
0–3	18	(30.5)	24	(33.8)	0.689	Referent		0.448
≥4	41	(69.5)	47	(66.2)		0.72	0.31–1.67	
Frequency of visiting children/relatives								
Daily	16	(27.1)	18	(25.4)	0.282	Referent		0.089
<Daily and ≥Monthly 1	28	(47.5)	26	(36.6)		1.03	0.36–2.89	
<Monthly 0	15	(25.4)	27	(38.0)		3.11	0.95–10.20	
Help available when needed								
Yes	57	(96.6)	66	(93.0)	0.358	Referent		0.430
No	2	(3.4)	5	(7.0)		2.03	0.35–11.70	

^aHigh burden is defined as those having a score >11 on Zarit Scale.^bAdjusted for age, sex, centre and care time of caregiver and severity of dementia and ADL level of patients.^cChi-square test.

weekly duration of informal care was increased by 8.5 h for those with mild and 17.4 h for those with moderate dementia compared to those with normal cognition, while people with severe dementia received an extra 41.5 h of care per week.

Demographic and socio-economic influences on dementia care

In Western countries, the majority of people with dementia living in the community receive care

Table 6. Proportions and odds ratios of the care received by people with non-dementia chronic diseases according to their socio-economic status.

	Care received by patients					Multivariate logistic analysis ^a		
	No (n = 1230)		Yes (n = 82)		<i>p</i> ^b	OR	95%CI	<i>P</i>
	n	(%)	n	(%)				
District								
Urban	677	(55.0)	46	(56.1)	0.852	Referent		0.153
Rural	553	(45.0)	36	(43.9)		0.64	0.35–1.18	
Educational level								
≥Secondary school	386	(31.4)	28	(34.1)	0.602	Referent		0.060
≤Primary school	844	(68.6)	54	(65.9)		0.56	0.31–1.02	
Occupational class								
Non-manual worker	387	(31.5)	33	(40.2)	0.099	Referent		0.211
Manual labourer	843	(68.5)	49	(59.8)		0.69	0.38–1.24	
Annual income (RMB Yuan)								
≥10,000	674	(54.8)	42	(51.2)	0.529	Referent		0.305
<10,000	556	(45.2)	40	(48.8)		0.74	0.41–1.32	
Annual family income per person (RMB Yuan)								
≥10,000	746	(60.7)	51	(62.2)	0.782	Referent		0.721
<10,000	484	(39.3)	31	(37.8)		0.89	0.47–1.68	

^aAdjusted for age, sex, province and ADL.^bChi-square test.

(>75%)³ compared with only one-third in the present study in China. Most of those who did not receive care for dementia in the present study were more likely to have low levels of education, occupational class and personal income and live in rural areas. The finding that those who had four or more children received less care for dementia may reflect the association between low SES and dementia, since families with large numbers of children tend to experience socioeconomic deprivation.¹⁸ In contrast, the lack of association between annual family income and dementia care could indicate a mediating effect from the high level of social support.¹² Furthermore, the lack of association between SES and care received by people with non-dementia diseases in the present study suggests that the association between low SES and lack of care for people with dementia is more marked than for people with non-dementia diseases, indicating a unique effect of SES on dementia care in the community.

In the present study, rurality was found to have the strongest association with dementia care among the four indicators of SES which could be explained by the fact that people with dementia living in rural areas tend to have a combination of adverse socioeconomic factors including lower level of education, occupational class and income.¹⁸ This observation supports previous findings that rural living in China was associated with shorter survival after dementia

diagnosis compared to urban living.¹⁹ While health care systems in China encounter huge challenges in tackling the rapid rise in the prevalence of dementia, there is a greater need in reducing dementia care inequality arising from differences in SES.

Patterns of dementia care management and caregivers

Previous studies in Western countries have consistently shown that more females than males care for people with dementia,^{3,20} while our study found no sex differences among caregivers. A striking feature of the present study is the observation that almost half of dementia care was provided by the patients' children or children in-law (47.7%), while sons were four times more likely than daughters (81% vs 19%, $P < 0.001$) to provide informal care for a parent with dementia. The underlying reasons for this difference are unclear but may reflect Chinese culture where children tend to remain at home to care for their elderly parents, while family responsibilities are passed on to sons.²¹ A recent study comparing social and cultural influences on caregivers for dementia patients living in Australia and China indicated that Australian caregivers were more likely to be the care-recipient's spouse and to be older.²² Our study found that caregivers for people with dementia were more likely to be of working age than

caregivers for other diseases, which are similar to those in previous studies undertaken in low- and middle-income countries.²⁰ The commitments required by children to care for parents with dementia are socially and economically challenging in the face of the one-child policy over the past three decades in China.

Caring for people with dementia requires specific communication skills for health care professionals and, more importantly, for family caregivers to improve quality of life and well-being of the patients.²³ The present study has demonstrated that compared to caregivers for non-dementia diseases, caregivers for people with dementia were more likely to have low education (primary school or below), which is consistent with findings from previous studies.⁷ This suggests that such caregivers may have less knowledge of health care and may find it challenging to undertake dementia care training. Consequently, the high levels of strain imposed by dementia care may cause deleterious effects to the physical and mental health of the caregivers. The shift care component or care shared among children or children in-law may exacerbate health problems of the caregivers including depression, increase tension and break down family harmony.²⁴ The characteristics of caregivers and care for people with dementia described in the present study are potential adverse factors for perpetuating intergenerational cycles of deprivation.

Burden of care for people with dementia

Our study has shown that caregiver burden in dementia measured by the Zarit scale was substantially higher than that for non-dementia diseases. Previous studies in Western countries have also shown high caregiver burden in dementia.⁷ In our study, stress levels of caregivers for people with dementia were consistently doubled compared to that of caregivers for people with non-dementia diseases. There are many factors associated with caregiver burden in people with dementia.²⁵ We have found high caregiver burden for dementia and other diseases in relation to low educational level and cutback on work as the result of care commitments by caregivers, suggesting that help, including training and financial support for caregivers, would be beneficial. Further evidence has emerged from our study showing that caregiver burden was cumulatively increased in caring for younger patients and living in rural areas, suggesting that more support should be directed to this high-risk group of caregivers.

Strengths and weaknesses of the study

The strengths in the present study include first, the multi-province data comprising urban as well as rural areas in China which provide compelling evidence

regarding the roles of SES that influence the dementia care. As far as we are aware, our study is the first to report the association between socio-economic deprivation and community care for people with dementia, highlighting inequality in dementia care. Second, a relatively large number of participants from community-dwelling settings that included both dementia and non-dementia conditions has enabled us to explore a wide range of important determinants of dementia care and caregiver burden. Third, the association between SES and dementia care was adjusted for the severity of dementia which was based on the probability calculated from the 10/66 algorithms and ADL level. Thus, our findings of dementia care inequalities in the community are robust. Limitations in our study include the omission of people with dementia and their caregivers from nursing homes or hospitals but these groups represent a small proportion since about 90% of people with dementia live with family in the community in China.²⁶ However, interpretation of our findings should only be applicable to older people living in the community. We analysed the data from the wave 2 survey from these provinces studies except for Hubei, where about 69% surviving cohort members took part in the survey. It is not clear whether this might have influenced the outcome of our findings. Subgroup analysis of data on care received 'a lot of time' or 'occasionally' was not performed due to small numbers while analysis of both groups together may have underestimated the impact of SES on dementia care and care burden.

In conclusion, there are a number of inequalities in dementia care and caregiver burden in China. Reducing the socio-economic gap and increasing education directed at high-risk caregiver groups may improve community care for people with dementia and preserve caregivers' well-being.

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Ethical approval

Obtained from the Ethics Committee of School of Health and Wellbeing, University of Wolverhampton, UK, and from the Research Ethics Committee of Anhui Medical University and the local governments in China.

Guarantor

RC is the guarantor for all content presented in this paper.

Contributorship

RC, ZH and LL designed the study and managed the data collection. RC and YC performed statistical analyses. RC and TSH wrote the first draft. AC, LL, YC and ZH revised the manuscript. All authors checked, interpreted results and approved the final version.

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